“Mrs Smith has no rehab potential”: Does rehabilitation have a role in the management of people with dementia?

Key points

- People with dementia are often deemed to have no rehabilitation potential and denied access to such services
- A sense of abandonment is common among carers
- Changing attitudes will require staff training and adequate resources to meet the needs of this growing population

Abstract

Rehabilitation is a *“process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients, service users and their family carers”* [1]. For older people experiencing illness, injury or disability the process of rehabilitation, which may include exercise, enables them to maximise their abilities and potential [2]. However, as demand for healthcare services grows alongside limited resources, clinicians often have to make decisions as to which patients may benefit from rehabilitation. The concept of *‘no rehabilitation potential’* often rears its ugly head in relation to people with dementia but what is it that informs this label, what is the impact and is it justified?

Rehabilitation is a *"process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients, service users and their family carers"* [1]. For older people experiencing illness, injury or disability the process of rehabilitation, which may include exercise, enables them to maximise their abilities and potential [2]. However, as demand for healthcare services grows alongside limited resources, clinicians often have to make decisions as to which patients may benefit from rehabilitation. The concept of *'no rehabilitation potential'* often rears its ugly head in relation to people with dementia but what is it that informs this label, what is the impact and is it justified? This negative stance towards people with dementia goes against the philosophy of positive support for both cognitive and physical rehabilitation [3].

Pressure on services to, for example, reduce length of hospital stay can result in rationing of care. I recently discussed this issue with a group of physiotherapists in Australia and when asked how they felt about this in relation to people with dementia was told by one *"we haven't got time and if they can't do what we say then we move onto those patients who can".* In effect, this approach blames the person with dementia for not fitting in with the physiotherapist's expectations of what they should be able to do. Negative attitudes towards dementia and a lack of knowledge and understanding of dementia have been found to limit the ability of some professionals to work in person-centred ways.[4]. In a person-centred healthcare system is the issue a lack of understanding, skills and resources of the rehabilitation staff required to meet the needs of the person and their families [5]? Denying access to opportunities for rehabilitation and to be able to work towards personal goals may be contributing to the increased risk of care home admission [6] but also may add to reduced wellbeing and quality of life for those with dementia and their carers. A sense of abandonment is common amongst carers as can be seen in these studies reporting the experiences of physiotherapy by people with dementia and their carers:

> *"…having got the physiotherapy people to come and see her they were soon very keen to get shot." [7]*

> *"He couldn't be mobilised by the two physiotherapists who came to see him once a day for 15 to 20 minutes. Mobilising someone with dementia was not a priority in acute care. Michael never regained his mobility" [8]*

Burton and colleagues [9] have suggested that limited carryover by those with dementia was a mediator for rehabilitation potential, along with poor motivation. Assumptions are made based on what pre-conceived expectations of people with dementia can and cannot do based on what we know about the condition. Not all dementias present in the same way so why would we assume that all people with dementia should be managed in the same way? For example, an apparent lack of motivation may be misunderstood by therapy staff and can be resolved by engaging with family [8]:

> *"The rehab staff said mum wasn't motivated. I told them that was because she didn't have her slippers. She wouldn't walk in bare feet at home without her slippers so no way would she walk on a hospital floor without them! As soon as she got the slippers, she did all her exercises".*

Although it has been reported that rehabilitation participation mediates the relationship between cognitive impairment and functional outcomes among those with hip fracture [10] is this because the approaches and strategies used aren't the best way to engage people with dementia? The evidence on the benefits of exercise for people with dementia is very variable on all outcomes including cognition, function and quality of life [11, 12] but the outcomes considered important by those affected may not be those traditionally collected such as pleasure [13] and social interaction. Where exercise interventions have been tailored to individuals there have been some benefits for function and reduction in falls [14, 15] and increased physical activity and physical health [16]. Different approaches are essential if we are to promote engagement with people with dementia and enable access to exercise, physical activity and rehabilitation interventions [7].

The attitudes we continue to see towards people with dementia will need to change as the population demographic changes and needs become increasingly complex with physical, cognitive and social needs. We need to increase the knowledge and skills of staff and teams to enable them to work confidently and effectively working with people with dementia. Those with the least access to rehabilitation are the ones who have most to gain so maybe we need to focus on those who need the most support to gain from rehabilitation and ensure they are supported by the most experienced and skilled staff.

References:

1. Sinclair, A. and E. Dickinson, *Effective practice in rehabilitation* 1998, London: Kings Fund.
2. World Health Organization, *Rehabilitation in health systems*. 2017: Geneva.
3. Clare, L., *Rehabilitation for people living with dementia: A practical framework of positive support.* PLOS Medicine, 2017. **14**(3): p. e1002245.
4. Bamford, C., A. Wheatley, C. Shaw, and L.M. Allan, *Equipping staff with the skills to maximise recovery of people with dementia after an injurious fall.* Aging and Mental Health, 2018. **in press**.
5. Hall, A.J., I.A. Lang, R. Endacott, A. Hall, and V.A. Goodwin, *Physiotherapy interventions for people with dementia and a hip fracture-a scoping review of the literature.* Physiotherapy, 2017. **103**(4): p. 361-368.
6. Knapp, M., K.C. Chua, M. Broadbent, et al., *Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register.* BMJ Open, 2016. **6**(11): p. e013591.
7. Hall, A.J., L. Burrows, I.A. Lang, R. Endacott, and V.A. Goodwin, *Are physiotherapists employing person-centred care for people with dementia? An exploratory qualitative study examining the experiences of people with dementia and their carers.* BMC Geriatr, 2018. **18**(1): p. 63.
8. Australia, A.s., *Dementia care in the acute hopsital setting: issues and strategies*. 2014.
9. Burton, E., V. Cavalheri, R. Adams, et al., *Effectiveness of exercise programs to reduce falls in older people with dementia living in the community: a systematic review and meta-analysis.* Clin Interv Aging, 2015. **10**: p. 421-34.

10. Lenze, E.J., M.C. Munin, M.A. Dew, et al., *Adverse effects of depression and cognitive impairment on rehabilitation participation and recovery from hip fracture.* Int J Geriatr Psychiatry, 2004. **19**(5): p. 472-8.
11. Lamb, S.E., B. Sheehan, N. Atherton, et al., *Dementia And Physical Activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: randomised controlled trial.* BMJ, 2018. **361**: p. k1675.
12. Lam, F.M., M.Z. Huang, L.R. Liao, et al., *Physical exercise improves strength, balance, mobility, and endurance in people with cognitive impairment and dementia: a systematic review.* J Physiother, 2018. **64**(1): p. 4-15.
13. Lindelof, N., L. Lundin-Olsson, D.A. Skelton, B. Lundman, and E. Rosendahl, *Experiences of older people with dementia participating in a high-intensity functional exercise program in nursing homes: "While it's tough, it's useful".* PLoS One, 2017. **12**(11): p. e0188225.
14. Wesson, J., L. Clemson, H. Brodaty, et al., *A feasibility study and pilot randomised trial of a tailored prevention program to reduce falls in older people with mild dementia.* BMC Geriatrics, 2013. **13**: p. 89.
15. Pitkala, K.H., M.M. Poysti, M.L. Laakkonen, et al., *Effects of the Finnish Alzheimer disease exercise trial (FINALEX): a randomized controlled trial.* JAMA Intern Med, 2013. **173**(10): p. 894-901.
16. Teri, L., L.E. Gibbons, S.M. McCurry, et al., *Exercise Plus Behavioral Management in Patients with Alzheimer Disease: A Randomized Controlled Trial.* Journal of the American Medical Association, 2003. **290**(15): p. 2015-2022.